

### **MEMORANDUM**

To: The Maine Guardianship Project, Systems Transformation Grant

From: Karen Glew, Office of Quality Improvement Services

Date: October 26, 2009

Re: Maine Guardianship Project Evaluation Activities

The attached report summarizes the following evaluation findings:

- Probate court public files in Cumberland and Lincoln counties in the Pre-Knowledge Period, prior to the modification and creation of court documents by the Maine Guardianship Project.
- Feedback of persons using the guardianship website at <u>www.maine.gov/dhhs/guardianship</u> and reading a "Guide to Understanding Adult Guardianship & Alternatives."

Information in this report can be used to better understand the characteristics of individuals being petitioned for guardianship in the probate court, the characteristics of the petitioner, the frequency of recommendations for alternatives to guardianship recommended by the court visitor and legal decision by the probate judge.

Based on the information examined during the evaluation processes educational materials and resources regarding alternatives to guardianship should be focused on those family members of individuals 18 years and younger or 56 years and older having a diagnosis of Developmental Disabilities, Autism, Dementia or Alzheimer's Disease.

In the majority of probate court cases reviewed, the probate court judge's in granting guardianship was consistent with the court visitor recommendations. Therefore, an emphasis on modification and creation of court documents should include the court visitor as well as the probate court judge.

Please contact me at (207) 287-4210 if you have any questions regarding this report or the evaluation activities of the System Transformation Grant.

# "Systems Transformation": Transforming Maine's Systems for Persons with Disabilities

### Purpose and Overview

The Maine Department of Health and Human Services (DHHS) was awarded a five-year Systems Transformation Grant from the US Centers for Medicare and Medicaid Services (CMS) in 2005. CMS provides funding and support through the Systems Transformation Grant to assist States to promote community-based services and supports by empowering individuals to make informed choices about long-term care.

A major goal area of this grant for DHHS is to *Increase Choice & Individual Control by Developing and Promoting Alternatives to Guardianship & Conservatorship*.

Since 2005 Maine's Guardianship Project has been working with an array of stakeholders, including probate judges, attorneys, public guardianship staff, clinicians, legal and self-advocates, schools and families to gain a better understanding of what people need to know about the guardianship and conservatorship process, what resources they need to educate themselves and others and recommendations to modify existing policies and procedures. This information is helping us create educational materials that all can understand, modify court documents to improve information collected and change policies and statutes as needed.

### Evaluation of Choice and Control Goal

The first evaluation component of this goal focuses on measuring the use of guardianship in Maine by collecting information from the Maine probate court files in the counties of Cumberland and Lincoln. The evaluation reviewed documentation provided in the court file regarding the petition and granting of guardianship. Documentation reviewed included: characteristics of individuals seeking guardianship and the incapacitated adult; physical and mental condition of the incapacitated adult; clinical information of the incapacitated adult; court visitor information; and final decision for type of guardianship granted. The evaluation occurred prior (Pre-Knowledge Period) to the modification and creation of educational materials and court documents and will occur after (Post Knowledge Period) the implementation. The overall effectiveness of this goal area's implementation plan will be determined by the adequacy of information collection and the ability of the system to make adjustments analysis, review and interpretation of the data collection from the probate courts.

The second evaluation component of this goal focuses on the resources and information that people need to educate themselves on guardianship and alternatives available to guardianship. In Spring 2009, the Maine Guardianship Project launched a website devoted to educating family members, friends and professionals on guardianship, alternatives and researching alternatives to guardianship. The website states that its purpose is to provide information and resources to 1) find the least restrictive way to provide care while continuing to support an individual's needs and 2) to help preserve an individual's right to make decisions about his or her life. The website at <a href="https://www.maine.gov/dhhs/guardianship">www.maine.gov/dhhs/guardianship</a> includes a brochure designed and produced by the Maine Guardianship Project titled "Guide to Understanding Adult Guardianship & Alternatives." Included in the brochure is a survey to help better understand the supports and resources needed by individuals to assist them in better understanding guardianship and alternatives to guardianship and how the information provided by the Maine Guardianship Project is helpful.

### **Evaluation of Maine Probate Court Public Records**

# Evaluation of Maine Probate Court Files Prior to Modification and Creation of Court Documents

During the summer of 2009, the DHHS Office of Quality Improvement Services (OQIS) began collection of the Pre-Knowledge Period with a random selection of probate files requesting a petition in probate court for individuals needing guardianship or conservatorship during 2006. OQIS collected unidentifiable information relating to characteristics of adult guardianship cases from hard copy probate files in Cumberland and Lincoln county courthouses. All information collected and reviewed were publicly available by the probate courts. OQIS used a data collection tool that was used by Jennifer Moye, PhD and colleagues in "Clinical Evidence in Guardianship of Older Adults is Inadequate: Findings from a Tri-State Study," <u>The Gerontologist</u>, 2007. Permission was obtained from Dr. Moye to modify the tool for our specific purposes (Attachment 1).

## Probate Court Pre-Intervention Evaluation: Demographics of Individuals Petitioned

#### Cumberland County

- A total of 42 out of a possible 138 cases were reviewed in Cumberland County.
- The gender for those individuals petitioned were almost split down the middle with 45.2% being males and 54.8% females.
- The majority (80.9%) of those individuals were 56 years of age and older (54.7%) or 18 years of age and younger (26.2%).

### Lincoln County

- In Lincoln County a total of 10 out of 20 cases were reviewed.
- The majority of individuals petitioned were males (60%).
- The majority (80%) of those individuals were 56 years of age and older (60%) or 18 years of age and younger (20%).

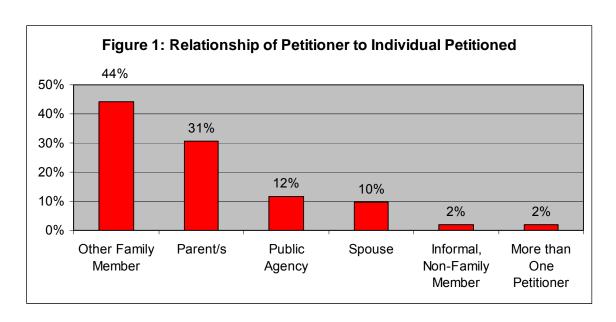
## Cumberland and Lincoln County Combined

- A total of 52 cases were reviewed.
- Of those 52 cases, 48.1% of individuals petitioned were male and 51.9% were female.
- The majority (80.7%) of those individuals were 56 years of age and older (55.7%) or 18 years of age and younger (25%)

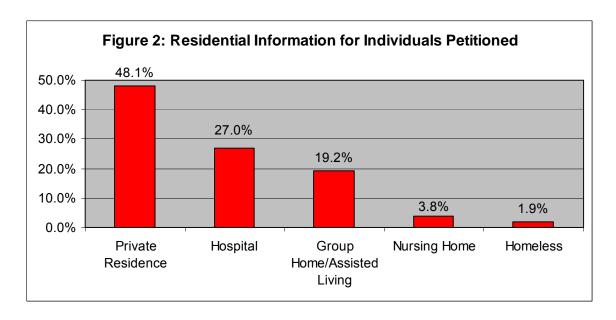
# Probate Court Pre-Knowledge Evaluation: Information on Individuals Petitioned and Petitioners

Requesting guardianship or conservatorship requires a petitioner to complete a petition for guardianship or conservatorship. A petitioner may be anyone requesting a court hearing to determine the competency of the petitioned individual. The petitioner is required to report on the petitioned individual's mental and financial status, obtain a physician/psychologist report and signature, and any other information deemed necessary for a competency determination by the probate court. Once all documentation has been submitted by the petitioner, the court will order a court visitor to meet with the petitioned individual. The court visitor will file his/her report in the probate court to assist the probate judge in a legal decision regarding the guardianship or conservatorship petition.

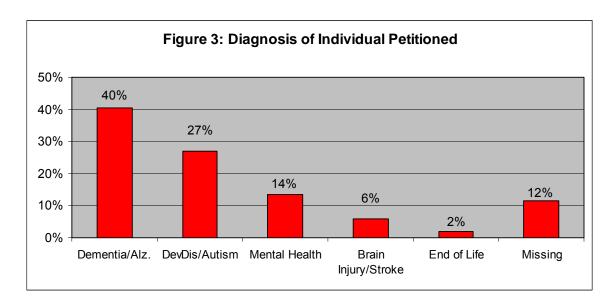
As part of the probate court file, information provided by the petitioner, clinician and court visitor was examined to better understand the incapacitation and current needs of the individuals being petitioned in a guardianship or conservatorship case.



• The majority (85%) of petitioners were family members



- One-half of the cases reviewed indicated that the individual petitioned for guardianship/conservatorship were living in a medical or staffed residence (hospital, group home, assisted living facility or nursing home) at the time the petition was filed.
- Nearly one-half (48.1%) of the cases reviewed indicated that the individual petitioned for guardianship/conservatorship were living in a private residence.



- Information on diagnosis was obtained from the petitioner's report and clinical report contained in the file. In a majority of the cases (88%), information on diagnosis between the petitioner's report and clinical report were consistent. However, in 12% of the cases information was not consistent. These cases consisted of missing information, lack of formal diagnosis or information that was not able to be deciphered due to written handwriting.
- The majority (40%) of cases involved a diagnosis of Dementia or Alzheimer's Disease.

	Figure 4: Diagnosis and Age of Individual Petitioned						
	Dementia/ Alz	DevDis/ Autism	Mental Health	Brain Injury/ Stroke	End of Life	Missing	Total
18 years or younger	0	10	1	0	0	2	13
19-21	0	1	0	0	0	0	1
22-55	1	2	1	2	1	2	9
56-75	4	0	4	1	0	1	10
76 years or older	16	1	1	0	0	1	19
Total	21	14	7	3	1	6	52

- The majority of individuals 18 years were petitioned for guardianship due to a diagnosis of Developmental Disability or Autism.
- The majority of individuals 56 years and older were petitioned for guardianship due to a diagnosis of dementia or Alzheimer's Disease.

## Probate Court Pre-Knowledge Evaluation: Determination of Need by Probate Court

Since the overall goal of the Maine Guardianship Project is to increase the use of alternatives to guardianship, information was collected to better understand the baseline of guardianship decisions prior to the implementation of revised court documents and protocols. Figure 5 illustrates the determination in cases granted while Figure 6 provides the type of guardianship granted by diagnosis.

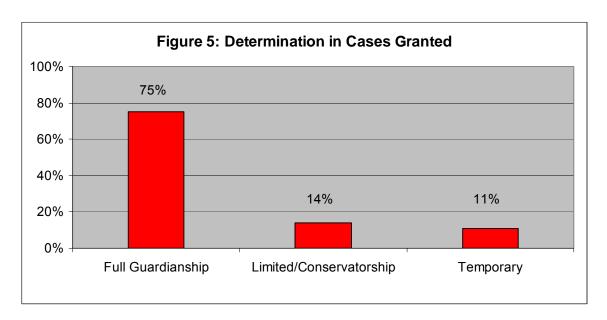


Figure 6: Type of Guardianship Granted by Diagnosis					
	Full Guardianship	Limited/Conservatorship	Temporary	Total	
Dementia/Alz. Disease	12	1	2	15	
DevDis/Autism	12	2	0	14	
Mental Health	3	2	2	7	
Brain Injury/Stroke	2	0	1	3	
End of Life	1	0	0	1	
Diagnostic Not Available	3	1	0	4	
Total	33	6	5	44	

- Of the 52 files reviewed, 44 cases were granted a decision. Cases not granted a
  decision included withdrawal of the petition or petitioned individual died prior to
  hearing.
- Of the 44 cases, the majority (75%) of individuals were granted full guardianship.

In addition to examining the frequency of guardianship decisions, OQIS compared probate judge decisions in guardianship cases compared to the recommendation of the court visitor. Based on the sample of case files reviewed, the probate court judge granted a decision consistent with the court visitor recommendations in 40 of the 44 cases.

### **Evaluation of Educational Materials**

As part of the "Guide to Understanding Adult Guardianship & Alternatives," a survey was designed by the DHHS Office of Quality Improvement Services in collaboration with the Maine Guardianship Project. The survey (Attachment 2) is optional and gauges a person's knowledge of guardianship and alternatives to guardianship before and after reading the brochure. Feedback obtained form the web-based survey will assist the Maine Guardianship Project to determine if the information contained in the brochure is helpful and what additional resources or materials would be useful for families, friends and professionals.

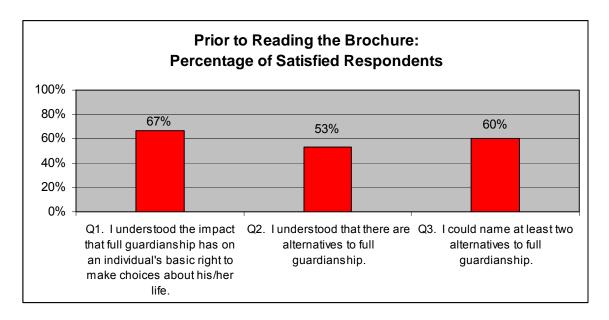
# "Guide to Understanding Adult Guardianship & Alternatives:" Survey Response Demographics

A total of 15 persons completed the web-based survey between April and October 2009. Of the individuals completing the survey: Return rate??

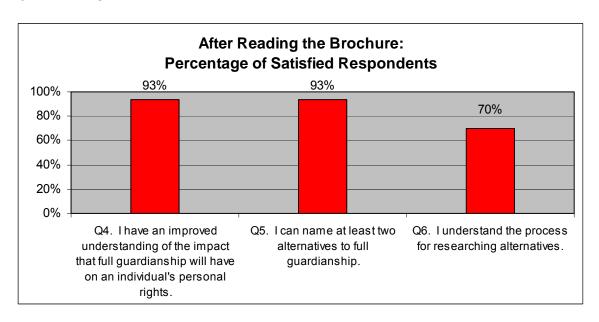
- Two-thirds (66.7%) of the survey respondents were female.
- Nearly half (46.6%) of respondents were from Cumberland County.
- The majority of individuals responding to the survey (40%) was a family member or friend.

# "Guide to Understanding Adult Guardianship & Alternatives:" Survey Response

# Before Reading Brochure



### After Reading Brochure



• Individuals responded that they had an improved understanding on the impact of full guardianship and alternatives after reading the brochure.

## **Summary and Recommendations**

The Maine Guardianship Project is in its fourth year of the Systems Transformation Grant. This report focused on an evaluation of the probate court public files in the Pre-Knowledge Period and the feedback of persons using the guardianship website. Based on the information examined in those evaluation processes:

- The majority of individuals petitioned for guardianship
  - Have a diagnosis of Dementia/Alzheimer's or Developmental Disabilities/Austism.
  - o 18 years and young or 56 years of age and older.
- The majority of petitioners are family members.
- Two-thirds of the cases reviewed resulted in being granted a full guardianship.
- In 40 of the 44 cases appearing in the probate court, the probate judge's decision as consistent with the recommendation of the court visitor.
- The majority of individuals responding to the web survey were:
  - o Female
  - o Residing in Cumberland County
  - o A family member or friend
- Individuals responding to the survey indicated that their understanding of guardianship and alternatives improved after reading the brochure.

#### **Next Steps**

The DHHS OQIS is committed to working collaboratively with Maine's Guardianship project as request to communicate findings of evaluation activities and using information obtained in the evaluation to assist in the creation and modification of court documents and education materials to improve information collected and change policies and statutes as needed.

OQIS will continue to evaluate the activities of the Maine Guardianship Project. Next steps are to:

- Based on information obtained in this report, design and implement interviews for the Probate Judges and Court Visitors.
- Conduct a Post-Knowledge Period evaluation of the 2009 probate court public records
- Continued analysis of the website survey.

# **APPENDIX**

# **Appendix 1---Web Survey Results**

		2009					
Survey Area	Survey Question	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	TOTAL
Diana diana	Q1. I understood the impact that full guardianship has on an individual's basic right to make choices about his/her life.	4	6	1	3	1	15
Prior to reading the brochure	Q2. I understood that there are alternatives to full guardianship.	5	3	1	5	1	15
	Q3. I could name at least two alternatives to full guardianship.	4	5	0	3	3	15
	Q4. I have an improved understanding of the impact that full guardianship will have on an individual's personal rights	8	6	0	1	0	15
	Q5. I can name at least two alternatives to full guardianship.	9	5	1	0	0	15
After reading the brochure	Q6. I understand the process for researching alternatives.	5	7	3	0	0	15
	Q7. I understand when full guardianship is appropriate.	3	8	2	2	0	15
	QB. I understand that there are several different types of guardianship, some being more restrictive than others.	10	5	0	0	0	15

Q9. I found the information on the following topics most useful	Number of Survey Responses	TOTAL
Facts about guardianship	10	15
Facts about alternatives to full guardianship	9	15
List of alternatives to full guardianship	8	15
Tips on how to research alternatives	5	15
Stories about what other adults have learned about guardianship	6	15
Tips on when full guardianship is appropriate	10	15
Tips on what individuals can expect under full guardianship	7	15

Q11. I am researching guardianship because:	Number of Survey Responses	TOTAL
A loved on is experiencing a difficult time	4	15
I serve as a guardian	1	15
I am helping someone explore guardianship options	5	15
Other	6	15

Q12. County	Number of Survey Responses
Androscoggin	1
Cumberland	7
Kennebec	1
Penobscot	1
York	2
Missing	3
TOTAL	15

Q13. Gender	Number of Survey Responses
Female	10
Male	3
Missing	2
ТОТА	AL 15

Q14. Age	Number of Survey Responses
Age 22 through 34	3
Age 35 through 54	5
Age 55 through 64	5
Age 65 and Over	0
Missing	2
TOTAL	15

Q15. List of Roles	Number of Survey Responses
Legal Professionals	1
Social Service Professionals	4
Family Member or Friend	6
Other	3
Missing	1
TOTAL	15

# **ATTACHMENT**

# **Attachment 1**

# Maine Guardianship Evaluation Review Instrument 2009

Information the AIP demographics from anywhere in the file			
Gender 1 □F 2 □M 3 □?	Age or □? (code 999)		
Ethnicity	Race		
1	1 □ American Indican/Alaska Native		
2	2 🗆 Asian		
	3 □ Native Hawaiian or other Pacific Islander		
	4 □ Black or African American		
	5 U White		
	6 □ Other		
Current Place of Residence	Marital Status		
1  Home	1   Married		
2 □ Nursing Home	2 □ Unmarried		
3 □ Medical Hospital	3 □ Unclear		
4   Psychiatric Hospital			
5   Hospital, not sure what type			
6  Assisted Living			
7 □ Unclear			

Information from the <b>Petition</b>		
Petitioner	1    Family	
	2 □ Friend	
	3 □ Agency	
	4  Attorney	
	5 🗆 Other	
Reason for the petition (legal cause of	1 □ Mental Illness/weakness/disease	
incapacity)	2 □ Unable to care for person (MA:physical Incapacity)	
	3 □ Unable to make/communicate decisions (MA:physical incapacity)	
	4 □ Other	
Limitations/Requests in the petition	Check all that apply: A □ Authorization to commit/admit	
	B   Consent to extraordinary medical procedures	
	C   Treat with antipsychotic medication	
	D 🗆 ECT	
	E □ Discharge to NH /Placement	
	F □ Financial needs	
	G □ Medical needs	
	H □ Personal Care	
	I □ Other	
DSM Diagnosis of the AIP stated 0 □ N 1 □ Y	Description of Less Restrictive Alternatives tried  0 □ N	
Check all that are provided A □ Dementia /AD/VD	Check all that are provided A □ Power of attorney	
B   Depression	B □ Additional Support from elder services	
C 🗆 Schizophrenia	C □ Additional Support from family/friends	
D 🗆 Delirium	D 🗆	
E   Alcohol use	E 🗆	
F 🗆 Bipolar disorder	F 🗆	
G   Medical conditions	G 🗆	
<b>H</b> 🗆	н 🗆	
I □ Other	I 🗆	
Are any specific 0 \( \subseteq N \) 1 \( \supseteq Y \) examples of problem behavior included?	If yes, what?:	

Information from the Clinical Evaluation				
Length words	Legibility of text 1 □ Handwritten 2 □ Typed			
	If handwritten			
	· /	5 (unreadable)		
Is demographic information provided by the clinician?	If Yes, Check all that are provided A Age	C Gender		
0 □ N 1 □ Y	B Ethnicity/Race	D Living Situation		
		D Marital Status		
Are the clinical examination procedures described??	If Yes, Check all that are provided A □ clinical interview	F □ nursing staff interview		
0 □ N 1 □ Y	B □ mental status testing (e.g., MMSE)	G □ psychiatrist consult		
	C □ neuropsychological testing	H □ neurologist consult		
	C □ CT/MRI of brain	I □ other		
	E □ Family interview	J □ none stated/unclear		
Is a diagnosis provided?	If Yes, Check all that are provided	E   Alcohol use		
0 □ N 1 □ Y	A □ Dementia /AD/VD	F   Bipolar disorder		
	B   Depression	G   Medical conditions		
	C   Schizophrenia	<b>H</b> 🗆		
	D   Delirium	I □ Other		
Is history described?	If yes, Check all that are provided A □ date of onset	C □ past treatments tried		
0 □ N 1 □ Y	B □ course of illness	D □ past services tried		
Is current treatment described?	If yes, Check all that are provided A □ current medications	C □ current services/ psychosocial tx		
0 □ N 1 □ Y	B   current medical treatment	D □ current housing		
Are cognitive or psychiatric symptoms described?	If yes, Check all that are provided  A □ cognition [memory, comprehension, reasoning, insight]	, judgment, orientation]		
0 □ N 1 □ Y	B □ consciousness [arousal, attention, coma]			
	C □ psychosis [hallucinations, delusions]			
	D   mood  Idenressed anxious poor modulation			

Is functional status described?	If yes, what? A □ eating D □ bathing/grooming				
ADL?	B □ toileting	E □ walking			
0 🗆 N	C □ dressing	F   motor/transfer			
IADL?	If yes, what?*	D = transportation			
0 □ N 1 □ Y	A □ money	D   transportation			
	B □ home care	E □ meals			
A	C □ health care	F   communication			
Are any specific examples of problem behavior included?	If yes, what?				
0 🗆 N					
Are there any direct or indirect comme	ents on prognosis?				
Is there any mention of family?		0   N			
is there any mention of family?		0 □ N 1 □ Y			
Is there any mention of the AIP's stren	ngths?	0 □ N 1 □ Y			
Is there any mention of the AIP's prefe	erences?	0 □ N 1 □ Y			
Are recommendations for limited guardianship provided?	1 □ person only				
General categories	2 □ finances only				
	3 □ not indicated				
Specific areas:	If yes, what?				
	A □ Authorization to commit/admit	F   Financial needs			
	B   Consent to extraordinary medical procedures	G   Medical needs			
	C □ Treat with antipsychotic medication D □ ECT	H ☐ Personal Care			
		I   Other			
		J None			
	E □ Discharge to NH /Placement				
Any thing else related to limitations?					

Information from the Judges Order			
Judges name	Type of guardianship granted 1 □ Permanent		
	2   Temporary		
	3 □ Emergency		
	4 □ Not granted		
Reason for the petition (legal cause of incapacity)	1 □ Mental Illness/weakness/disease		
	2  Unable to care for person		
	3 □ Unable to make/communicate decisions		
	4 🗆 Other		
Limited guardianship?	1 □ Person only		
General categories	2 □ Finances only		
	3 □ Plenary		
Specific areas:	Check all that apply: A □ Authorization to commit/admit		
	B □ Consent to extraordinary medical procedures		
	C □ Treat with antipsychotic medication		
	D 🗆 ECT		
	E □ Discharge to NH /Placement		
	F □ Financial needs		
	G   Medical needs		
	H □ Personal Care		
	I   Other		
	J None		
Any thing else related to limitations?			
In addition to the clinical evaluation, is there any other information in the file that the judge may have used to	Check all that apply: A □ GAL Report		
determine limitations?	·		
	B □ Court Investigator Report		
	C □ Affidavit		
	D □ Other		

# **Attachment 2**



# Systems Transformation Grant Choice and Control Brochure Survey

1.	Prior to the reading the brochure, I understood the impact that full guardianship has on an individual's basic right to make choices about his/her life.						
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
2.	Prior to the reguardianship.	•	hure, I understo	ood that there a	re alternatives to full		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
3.	Prior to the reguardianship.	_	hure, I could na	ime at least two	alternatives to full		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
4.	. After reading the brochure, I have an improved understanding of the impact that full guardianship will have on an individual's personal rights?						
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
5.	After reading guardianship.		can name at le	ast two alterna	tives to full		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
6.	After reading	the brochure, l	understand the	e process for re	searching alternatives.		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
7.	After reading	the brochure, l	understand wh	nen full guardia	nship is appropriate.		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		
8.	_		understand that ore restrictive t		eral different types of		
Stı	ongly Agree	Agree	Neutral	Disagree	Strongly Disagree		

9. I found apply)	d the information on the following topics most useful: (please check all that
	Facts about guardianship
	Facts about alternatives to full guardianship
	List of alternatives to full guardianship
	Tips on how to research alternatives
	Stories about what other adults have learned about guardianship
	Tips on when full guardianship is appropriate
	Tips on what individuals can expect under full guardianship
10. I woul	d like to see more information on the following topics (please describe)
Text b	ox
11. I am re	esearching guardianship because:
	A loved one is experiencing a difficult time
	I serve as a guardian
	I am helping someone explore guardianship options
	Other
13. Gende 14. Age—	y—drop down r—drop down -text box f roles—Legal Professionals



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